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How sociophenomenology of the body problematises the 'problem-oriented approach' to growth hormone treatment

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ABSTRACT

This article examines how people who are shorter than average make sense of their lived experience of embodiment. It offers a sociophenomenological analysis of 10 semistructured interviews conducted in the Netherlands, focusing on if, how, and why height matters to them. It draws theoretically on phenomenological discussions of lived and objective space, intercorporeality and norms about bodies. The analysis shows that height as a lived phenomenon (1) is active engagement in space, (2) coshapes habituated ways of behaving and (3) is shaped by gendered norms and beliefs about height. Based on this analysis, the article challenges what we label as the 'problem-oriented approach' to discussions about growth hormone treatment for children with idiopathic short stature. In this approach, possible psychosocial disadvantages or problems of short stature and quantifiable height become central to the ethical evaluation of growth hormone treatment at the expense of first-hand lived experiences of short stature and height as a lived phenomenon. Based on our sociophenomenological analysis, this paper argues that the rationale for giving growth hormone treatment should combine medical and psychological assessments with investigations of lived experiences of the child. Such an approach would allow considerations not only of possible risks or disadvantages of short stature but also of the actual ways in which the child makes sense of her or his height.

TREATING SHORT CHILDREN WITH GROWTH HORMONE

Short stature has been described as 'one of the most common concerns presenting to pediatric endocrinologists and other physicians caring for children' (Cohen, p. 4211).¹ This is the case, others have added, because short stature might be an indicator of certain diseases such as Turner syndrome or Prader-Willi syndrome and also because it is commonly regarded as an undesirable bodily mark.² In medical terms, children who are short for other than identified medical reasons fall into the category of idiopathic short stature (ISS). This is a statistical definition only possible by exclusion of all known medical reasons for short stature (such as small for gestational age or chronic renal insufficiency).³ Some countries, such as the USA, allow the use of human growth hormone treatment (hereafter referred to as hGH) to increase the height of children with ISS. However, debates are ongoing as regards ethical aspects of offering or not offering

such treatment. HGH has been defined as cosmetic endocrinology,⁴ enhancement⁵ or pharmaceuticalisation.⁶ The debate on the rationale for hGH treatment touches on different arguments¹ and has largely moved beyond the entanglement of aesthetics and health,⁷ focusing rather on the relevance of psychosocial disadvantage and stigma or possible practical limitations in everyday life⁸ or even possible physical and/or psychosocial disability.⁹ The Pediatric Endocrine Society recently stated that ISS is still a 'controversial indication' and stresses the need for further studies on the relevance of height for children and adults (Grimberg, p. 362).⁹

The aim of this article is to show *how* and *why* attendance to lived experiences of height is needed in bioethical and biomedical discussions of hGH treatment for children with ISS. The article proceeds in three steps. *First*, we describe the 'problem-oriented approach' to the debate on hGH treatment for children with ISS. In this approach, possible psychosocial disadvantages or problems of short stature become central to discussions about hGH treatment at the expense of first-hand lived experiences of short stature. This approach also centres more on objective and quantifiable measures than on height as a lived phenomenon. *Second*, we offer a sociophenomenological analysis of whether and, if so, when, and how height matters for interviewed adults in the Netherlands who are shorter than average without any known medical reasons for their short stature. *Third*, we show how our sociophenomenological analysis of the interviews contributes to biomedical and bioethical discussions on using hGH treatment for children with ISS. Based on the sociophenomenological analysis, we critically engage with the problem-oriented approach, through the short-stature-specific quality of life tool called QoLISSY. We understand QoLISSY as an example of a tool that harmonises with the problem-based approach and explain why this is problematic.

THE PROBLEM-ORIENTED APPROACH

Since the 1930s, various attempts have been made to increase height, including, for example, anabolic steroids, leg lengthening surgery and cadaveric growth hormone.⁶ In 1985, recombinant

¹Besides disagreements on the rationale of hGH treatment, other ethical issues of giving hGH treatment to children with ISS concern cost-effectiveness and uncertainties about both long-term safety and increase in quality of life of treated children.



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hGH was produced in laboratory, overcoming previous technical problems and allowing improved safety and larger drug supply. Since then, hGH treatment has been used worldwide as a replacement therapy for children with growth hormone deficiency (GHD)ⁱⁱ or as a therapy to gain metabolic benefits as in the case of Turner syndrome,² but in some countries (such as the USA), it has also been used to increase the height of children with ISS.⁶ⁱⁱⁱ hGH treatment is currently prescribed in the Netherlands for six medical conditions.^{iv} Even though hGH treatment has not received regulatory approval in Europe for general administration to children with ISS, it is available via 'off label' prescriptions.^v

ISS is the term used to identify children whose height is below -2 SDs for a given age, sex and population group.³ Although various clinical studies and evaluations have been made to assess the risks and benefits of hGH treatment for children with ISS, uncertainties remain about the long-term side effects.^{1 10 11} Therefore, recombinant hGH has not been granted marketing authorisation in Europe for the indication of ISS.¹² Recently, in the USA, the Pediatric Endocrine Society has recommended some restrictions on its use.⁹ Concerns have arisen regarding the long-term safety and about the rationale of the treatment.

The category of ISS has received particular attention in the biomedical and bioethical debates on using hGH treatment for two main reasons. First, unlike children with other conditions treated with hGH, children with ISS do not have any known medical conditions that result in short stature. While categories such as Turner syndrome and Prader-Willi syndrome are recognised diseases for which short stature is one of the symptoms, this is not the case for ISS.⁶ Second, there is considerable disagreement around the status of ISS. Some scholars see it as a category that describes children as shorter than the average yet as part of the continuum of healthy bodily variations. Gill 2006, for instance, defines children with ISS as *small normal children*.¹³ Others understand ISS as aligned with the notion of *idiopathic* conditions, considering them to be disorders for which no cause is currently known but for which one is anticipated to exist.¹⁴

The main reason given in biomedical and bioethical literature for increasing the height of children with ISS is that short stature might cause psychological and social problems,^{1 15} based on the idea that short stature is a burden that carries social stigma and disadvantage.^{16 17} The perception of short stature as something primarily negative, including prejudice against short individuals, is commonly referred to as heightism.¹⁸ Some studies do indicate associations between short stature and different social aspects, in particular for men, such as lower social status (in France¹⁹ and in the Philippines),²⁰ lower chances of getting married (in Italy)²¹ or greater risk for psychosis or suicide (in Sweden).²² Nonetheless, no proven relation exists between behavioural,

psychological and social problems and short stature^{16 23 24} nor is there any evidence that hGH treatment might improve psychological functioning.^{25 26}

Several studies in psychology and quality of life literature have also focused on whether or not children with ISS are at greater risk of psychosocial problems. Some studies claim that short stature is related to an increase in developmental, social and educational problems.²⁷ Others argue that since short people are perceived as less competent, they are more likely to be disadvantaged in the workplace and have lower positions.²⁸ However, many studies that show psychological problems have been criticised for their methodological limitations, lacking, for instance, a control group of average height children²⁹ or including only those children who were referred to the endocrinology clinic (as opposed to those who never consulted doctors because of their height).¹⁶ Some other studies, instead, show that children with ISS show no relevant difference from children of average height in terms of psychosocial problems.²⁴ Moreover, while some studies focus on the group/population level,³⁰ others recommend looking primarily at individual variations.³¹

In this paper, we label the discussions about hGH based on the idea that short stature might be a psychosocial problem as 'the problem-oriented approach'. This approach argues that hGH treatment aims primarily at the 'prevention and treatment of potential risks for psychosocial development' (Noeker, p. 81)³ and considers short stature to be the 'primary outward trigger of stress' (Noeker, p. 80).³ While there are some variations to this approach—for example, some claim the main sources of psychosocial burdens are the negative stereotypes regarding short stature rather than height itself^{15 32}—the problem-oriented approach arrives at the conclusion that hGH treatment is recommended because height increase might *prevent risks of future presumed or potential disadvantage* or *increase* quality of life of children with ISS.^{1 3 9 15 32} Further, what we label as the problem-oriented approach deems objective and quantifiable height as central to discussions on growth hormone treatment in the sense that it sees height as *the cause and solution* to potential problems for children with ISS later in life.

A SOCIOPHENOMENOLOGY OF THE BODY

Against this background, this study offers a sociophenomenological analysis of the lived experiences of short stature that draws on phenomenology of embodiment.

Phenomenology of embodiment

Phenomenology of the embodied self as being-in-the-world offers detailed explorations of the role of the body for subjectivity, including how lived embodied experiences of illness, pain or impairment can affect a person's bodily self-awareness, body image and agency.^{33–37} It also explores lived experience of the body, with a particular sex, of a particular age, race and ability.^{38–40} It explores how medical interventions modify bodies and what such modifications mean for subjectivity and agency, for example, in relation to intersex conditions,^{41 42} breast reconstructions after cancer⁴³ or disfigurement.⁴⁴

Phenomenological reasoning starts from the understanding of subjectivity as *embodied* and *situated* in the world and in relation to others, where our basic mode of being is pre-reflective and practical, and where any 'independent agency is intrinsically dependent on the situation in which it is articulated' (Käll and Zeiler, p. 101).⁴⁵ The embodied self is understood as never just consciousness, nor just a thing, but always both in an ambiguous relation to each other. As put in a formulation that seeks

ⁱⁱGHD is diagnosed when the pituitary gland, the gland in charge of secreting growth hormone (GH), does not produce enough GH to allow the correct development of the child.

ⁱⁱⁱIt is worthwhile to mention that it exists also an oestrogen treatment to reduce tall girls' height. See, e.g., the articles: Lee and Howell (2006),⁶⁶ or Rayner *et al* (2010).⁶⁷

^{iv}Pediatric conditions currently approved for hGH in the Netherlands are GHD, chronic renal insufficiency, Turner syndrome, Prader-Willi syndrome, small for gestational age and growth failure after a stem cell transplantation (<http://kindengroei.nl/behandelingsindicatiestelling-vergoeding/>).

^vSchönbeck *et al* (2013) write that 'the Dutch referral criteria require children with a height SDS of less than -3 SD to be referred for short stature' (Schönbeck, p. 371).⁵⁵

to capture what phenomenologists commonly refer to as the bodily ambiguity of the lived body: 'I am the body that I have' (Slatman, p. 168).⁴⁶ In this reasoning, the lived body is and sets the conditions of possibility of perception and action, and the body that someone is, is also what this person can experience as thing-like.

Furthermore, our bodily mode of being-in-the-world is constituted of 'the context of meaningful relations with which we are involved' (Diprose, p. 241, 239).⁴⁷ The notion of the lived body, then, refers to the 'intertwining' of body and world (Merleau-Ponty, p. 138).⁴⁸ The lived body is a lived relation to a (material and social) world immersed in meaning. It is the site of self-becoming 'in which the interface with others—both objects and living beings—constructs a dynamic self in which abstract singularity plays no part' (Shildrick, p. 110).⁴⁹

This study explores the experience of being shorter than average, focusing primarily on the intertwining of the *lived* and the *objective space, intercorporeality* in relation to others and things and *lived norms* understood as follows.

First, the phenomenological focus on lived experiences of height allows for distinguishing between *objective space*—that is, the physical, geometrical, conceptual space—and *subjective space*—that is, the lived, phenomenal, practical space which can be experienced differently, for instance, with changes in our moods or our bodily abilities.^{37–50} *Lived space* emerges from the relationship to our environment that is both produced and perceived, in continuous construction and with variable relations with objective space. According to Merleau-Ponty, one would not say that one's arm 'is beside the ash-tray in the way in which the ash-tray is beside the telephone' (Merleau-Ponty, p. 98).⁴⁸ The spatiality of the body 'is not, like that of external objects or like that of 'spatial sensations', a spatiality of position, but [it is] a spatiality of situation' (Merleau-Ponty, p. 100).⁴⁸ This formulation stresses the spatial and temporal unity of the body being involved in its tasks. The body is not merely 'in space, in time' but 'inhabits space and time' (Merleau-Ponty, p. 139).⁴⁸ The embodied subject's inhabiting space is a matter of time and movement. It is about our 'moving in relation to things,' which is 'independent from the abstract conception of space' (Morris, p. 115).⁵¹

Second, the embodied self inhabits a social world, and the embodied self as being-in-the-world is always being-with others. This idea is already part of the reasoning on the lived body as a site of self-becoming, constituted by dynamic relations with others, things and the world. Scholars have used the notion of *intercorporeality* to emphasise the non-discreteness and basic openness of bodies, and the relational becoming of bodily selves (where singular, that is, unique and different, lived bodies are continuously shaped and come to be in exchanges between bodies).^{45–52–54} In this article, we use the concept of intercorporeality to refer to the ways embodied subjectivity and agency is shaped dynamically in relations with others and things.

Third, phenomenology has examined how norms and beliefs about specific bodies can become incorporated—through being repeatedly enacted and expressed—into someone's lived body.^{41–42} Such work has examined how bodily expressed or enacted assumptions and norms that are deeply engrained in our habitual bodily existence, experienced 'as of-a-piece' with our existence, can help shape the things we simply do and intuitively feel that we should do (Zeiler, p. 82).⁴¹ Incorporating assumptions and norms into someone's lived body can enable seamless interaction as long as others have incorporated similar assumptions and norms through a tacitly shared bodily know-how.

Methodology

Our analysis builds on interviews conducted in the Netherlands in 2016 with 10 people between 18 and 52 years old who are shorter than average. The Netherlands has the tallest population of any country in the world, with an average height of 183.8 cm for men and 170.7 cm for women.⁵⁵ We interviewed six women ranging from 150 cm to 159 cm and four men between 166 cm and 169 cm.^{vi} The first author used three main recruitment methods: she sent out information about the research via Dutch associations for little people, via information flyers (in person and through social networks) and used snowball sampling. Only one participant was recruited through an association.

Staying attuned to interviewees' lived experiences of height as narrated from a first-person perspective, we pursued what one of us has labelled a 'sociophenomenology of the body' (Slatman, p. 555),³⁴ and attended to the interviewees' narrated experiences, paying attention to sociocultural dimensions. We also attended to material dimension of bodily existence and coexistence.⁵⁶ The interviews focused on participants' narrations of their everyday experiences of height, including narrations of situations in which they came to think about or note their height. At the end of the interviews, participants were also asked about their experiences with and/or knowledge of hGH treatment.

Only two participants did not know of any medical interventions for short stature before the interviews, while the others had heard about hGH treatment. Four had more direct experiences: three when they were children and were informed by the doctors that hGH treatment might have been an option for them and one when hGH for was proposed for his daughters. They all refused hGH treatment, and no one had direct experience with it.

Interviews lasted on average 1 hour. They were digitally recorded and then transcribed verbatim. The first author conducted and transcribed all the interviews, while the three authors read the transcripts line-by-line and interpreted the data. In the analysis phase, the collected data were interpreted by using the phenomenological hermeneutical method.^{57–vi} Applying this approach to the collected data, the authors first attributed open, descriptive codes to excerpts of the interviews that were related to participants' experiences and reflections on height. Examples of these codes include figurative height, being used to it, others' behaviour, comparison with tall/short people, look up/down, gender discourse. Second, on the basis of these codes, the authors identified three general themes, and engaged with these themes via the conceptual framework of sociophenomenology of embodiment. The three identified themes are (1) height is narrated as active engagement in space, in and through relations with others, (2) height coshapes habituated 'I can' through intercorporeal exchanges with others and things and (3) the meaning of height is framed by incorporated gendered norms and beliefs.

Ethical considerations were addressed in all phases of the research process. All participants provided written informed

^{vi}All pathological conditions, such as achondroplasia or GHD, were excluded.

^{vii}We use the phenomenological hermeneutical method to pursue our sociophenomenology of the body for two main reasons. It required us to explore participants' lived experiences attending our taken-for-granted prejudices and assumptions on height through self-reflectivity. It also allowed us to engage in an interpretation of the empirical data that examines the situated and embodied experiences of participants, with a focus on the sociocultural and material aspects of embodied and situated coexistence.

consent to the study. Transcribed interviews were anonymised, and all personal data were kept confidential and locked in a safe.

MAKING SENSE OF HEIGHT

Height as active engagement in space

This first theme addresses the ways participants narrate their own height in and through relations to others in their daily embodied engagement in space. Most of the interviewees define themselves as not ‘very short’, just on the edge of the study requirements. While Frank claims ‘I am quite short, but not *too* short’ [our italics], Jack acknowledges that he is shorter than the Dutch average but describes his height as ‘acceptable’. In all the interviews, *objective* and *lived height* seem to intertwine; they overlap and shape each other, with reference to a variety of images and qualitative representations. For instance, when Hannie mentions people that she considers short, she refers to them as ‘a head shorter’ than she is. She also claims that she needs to ‘stand up’ to say how much shorter they are. Hannie explains: ‘because I don’t know how tall I am... I don’t know, like this? [pointing at her shoulders]’.

Most of the participants explain that in everyday life, they only occasionally become aware of how tall they are. As put by Jack, he does not think about height unless he meets someone who is as tall as he is: ‘If I see someone who is maybe the same height as me or maybe smaller, then, then I really think “Wow, he’s small!” and then the next time I think “Shit, I’m the same height”. You know?’ Jack continues:

I do see, I do notice that other guys, especially guys, are small too. I think ‘Oh, this is a small guy’ but I’m the same height. So, that’s funny that you do see it, that another guy is smaller than the average Dutch guy and, and then.... Yeah. So, it’s noticeable also for me, that I’m the same height.

Other participants recount similar experiences of sometimes noting their own height in interactions with others. Some, such as Milly and David, explain that they become aware of their height primarily when *others* make remarks.

When participants talk about their own height, objective and quantifiable descriptions are mostly overshadowed by their accounts of how they *live* their height. Recounting a mundane situation, Milly says:

When I’m walking with my boyfriend, we’ve been together for 12 years now, he is 183 [cm]. I don’t feel he is like really a lot taller. Only 30 cm, that’s like this [indicating with her hands], so...

Besides the measurement in centimetres, Milly refers to *her* own body to define *her boyfriend’s* height. Even if she states that there are positive and negative aspects of being shorter than average, she has an overall positive narrative. She says that her boyfriend is attracted to her short stature, and that she is proud of being short. She says that she would not like to be taller, because if she were, she would lose something that makes her ‘unique’. Milly also comments that when she compares herself with others who are taller, she does not feel small. It is others who are ‘really’ tall. While she measures 20 cm below the average Dutch woman, her attention focuses on others’ *tallness* rather than her *shortness*.

When people are ‘really’ tall, Milly says that she feels ‘sorry’ or ‘pity’ for them because they might have problems in daily life. For instance, she says ‘sometimes that’s a problem for me as well [finding clothes of the right size], but when jeans are too long, I can make them short. When you are tall, they are just too short, you cannot make them longer’. Talking about sports,

Milly adds that it is ‘unhealthy’ to be really tall as ‘everything is out of balance’. On a similar note, David comments that even if taller people might be stronger than he is in general terms, he is ‘relatively very strong’ because he is more ‘aerodynamic’ than they are, and he can easily support his own weight in gymnastics. David’s narrative also changes according to the perspective he takes on his height. He recounts that when he looks at a particular picture of himself standing next to other people, he wonders about what others might think. He says that he asks himself whether they would ‘think less’ of him looking at the same picture. Maybe they would see him as deserving less consideration, or they would consider him as less important than others. This attention to his body as an object, as if he were looking at it *from the outside*, could be understood as revealing some of his insecurities and can be contrasted with his description of his everyday engagement with the world, where he talks about his height in more positive terms (as, for instance, in sports, as mentioned above).

These interviewees’ accounts and descriptions emphasise what is often referred to as the pre-reflective level of embodied experience, where one does not attend reflectively to one’s own body, *and* to how height sometimes becomes thematised (i.e., something the interviewees attend to) in and through relationships with others. Such thematisation happens in participants’ everyday engagement with the world: they assign meaning to height when they *do things*, *when they engage with others and move in space*. To clarify this point, we suggest a neologism that transforms height into a verb rather than a noun: ‘heighting’. In formulating this concept, we draw on Kevin Aho’s⁵⁸ parallel between Merleau-Ponty’s and Heidegger’s conceptions of spatiality. Aho refers to Heidegger’s idea of ‘bodying-forth’ (Leiben) of the body (Aho, p. 10)⁵⁸ to highlight the similar phenomenological understanding of space in the two authors’ work. Both Merleau-Ponty and Heidegger understand space not merely as an external relationship with things, like a ‘container within which objects of experience reside’ (Aho, p. 10),⁵⁸ but also ‘in terms of pre-objective, everyday involvement, in terms of the constant dialectical interplay between the ‘bodying-forth’ of the body and the things that it encounters’ (Aho, p. 2).⁵⁸ Just as bodying-forth is used as a verb, ‘heighting’ can be used as a verb for the way it helps stress the active and dynamic engagement—height in the ‘doing’—described by interviewees. Participants describe lived height by the way in which they *inhabit* it. Moreover, height is described as ‘spatiality of situation’ rather than ‘spatiality of position’ (Merleau-Ponty, p. 100),⁴⁸ which means that participants, as always already immersed in a sociocultural context, actively respond to an actual surrounding, and make sense of themselves and their height in relation to that surrounding. The notion of heighting is intended to conceptualise what was central to this theme: from the lived perspective of the interviewees, height was made meaningful through active engagement in space—through action and interaction.

Height, others and things coshape habituated ‘I can’

In participants’ accounts and narratives, lived height acquires meaning in spatial engagement and in concrete corporeal exchanges. Some bodily interactions with others and objects are repeatedly described as carrying special meanings for interviewees in terms of shaping how they behave. Among these interactions, the *direction of one’s gaze* and the *ability to see* carry particular significance. Participants often mention that they have to ‘look up’ at taller people while talking, or that at social events they ‘can’t see’ properly because there is someone

or something obstructing their view. Linda recalls that during a concert she *could not see* the show on stage because of the hairstyle of the person sitting in front of her. She still prefers to sit during concerts because when she stands, she says, she normally looks at people's back. She attributes some of her choices and actions to her 'limited gaze', for instance when describing how she avoids crowded places because she cannot 'breathe' properly. This feeling even induces her panic attacks:

I didn't want to go there [to a city festival] because, because if you are smaller, everyone is bigger than me and it's crowded, and I can't see anything. I have panic attacks, then. It started a couple of years ago for the first time. And that's, I think that's related to being small. Because if you are big and you can see above everybody it's not scary, but if you are small and you can't see anything it's... it's... it's scary. So, that makes me panic.

Crowded places scare Linda, who attributes her visual limitations to her height. Being the shortest person among taller people creates the feeling that crowded events are inhospitable situations that, she says, she prefers to avoid. Linda has an overall negative narration as she recounts that being short is sometimes difficult for her. She claims: 'nobody likes to be short', and she is the only participant who mentions that she felt she needed to join an association for short people, just to be with others 'who are also small'. At first, it was strange to her because, she says, 'I was always used to look up at somebody and now I had to look down. So, that was very, very strange. But it's, it's...now I don't see it anymore'. While at first it was an unusual situation, now she feels 'at home over there'. The fact that for once she can 'look down' at others is described by Linda as playing a role in her *feeling at home*, as if her gaze's direction makes her closer to the members of the association.

This sense of *familiarity* with shorter people is expressed also by Luisa when she says that she 'kind of connected' with a girl at school because—even if this girl was shorter than she was—they were 'both small'. Similarly, Jennifer says that being with people of the same height 'feels nice for some reason'. The fact that *others* are 'looking down' at her is an issue of inequality, she says. She contrasts this idea with her experience of being with people who are similar to her own height: 'connecting to a short person is not, it's just equal'. She also attributes the fact that some people who are taller than her believe that she is younger than she is, or do not take her seriously, to the direction of their gaze. Jennifer says that looking down is 'offensive' and she likes being with shorter people because she feels 'more powerful'.

In these accounts, the direction of one's gaze is described as *doing* something to participants, whereas Frank describes himself as *doing* something with it. He shares the view of some of the other interviewees that taller people have 'a natural preponderance' because they 'look over' shorter people. Taller persons have a sense of control, Frank argues, and explains: 'in Dutch you say *'overwicht'*. [...] It's like you have a natural balance in favour of you in social communication or interaction'. Thus, Frank holds that, since he is short, he holds an apparently weaker position, a disadvantage, but that he can transform it into a benefit. He claims that his 'underdog' position, his original 'unfavourable position' gives him freedom:

And then, that gives you an advantage. Because you can change this. Whereas, say, if you are in a favourable position, then you have to maintain that. Because I have the leverage even to give them the stereotypical feedback, the stereotypical image, and then turn it around when it suits me. So, it gives you an advantage as well.

While Frank portrays himself as enjoying the freedom to 'play' with stereotypes^{viii} and other people's expectations thanks to his height and to the way he looks at others and they look at him, Jack says that, for him, the gaze's direction, whether one 'looks up' or 'down', does not have any special meanings. Jack instead focuses on *being able to see*. When he goes to concerts, he says, he makes plans beforehand, in order to get the best visual position. Situations in which participants must make adjustments to *interact* with objects is also a recurring point in all interviewees' narratives. These adjustments are made, for instance, when reaching for high shelves, driving a car or seeking clothes that fit. Jack describes his experience at the supermarket:

When I'm in a supermarket, and there is the funny thing, you have those cooler shelves with the doors, the cooler office, the refrigerators, the big ones, mostly the top things, like butter or something, I don't know. I cannot get there because it's too high for me, and I have to get up like, like, like on a step. And then people see me like this tiny guy reaching out the highest stuff in the supermarket. I don't have an issue with that because I think it's funny so I'm happy that people think it's funny too.

This narration is in line with Jack's overall positive account. He stresses that being short is a reason for pride for him. While recounting several situations in which he looks 'funny' because of the way he interacts with objects, he portrays himself as having 'the little brother type of personality'. He claims that being short is something that makes people see him as 'friendly' and 'nice', and he easily gains sympathy from others who somehow are inclined, he says, to 'protect' him. In other words, Jack describes his bodily interactions with others and objects as having an impact on how he is perceived—on how his personality is perceived.

From the perspective of the embodied self as being-in-the-world, things—such as tall refrigerators or high shelves—appear to the individual depending on what one wants to do, but certain shelves that are placed high on the wall will also stand out as insurmountable depending on their place on the wall in relation to one's lived body, and in relation to whether there are steps available and whether the situation is experienced as comfortable enough to climb up and reach the 'highest stuff'. In this way, the perspective of the embodied self as being-in-the-world allows us to hold together materiality, sociality and affect in the analysis. There is also a temporal dimension: how one perceives present situations can be shaped by past experiences, such as not reaching things, and past interaction with others.⁴⁵ In contrast to Jack's narration, Linda tells of her experiences of not reaching things while doing gymnastics:

Well, I, to be honest, I hate sports. And, and I used to... I didn't like gymnastics in school, either. I hated it. But because they had to change everything for me. I mean, if we had to do something, it was too high for me so, so they had to make it smaller and everything. So, and, well, I didn't like it.

These accounts focus on basic relational becoming of bodily selves where singular, lived bodies are continuously shaped and come to be in exchanges between bodies (i.e., the intercorporeality of the embodied self) and on how things such as high shelves or machines are perceived as impossible to reach, as hindrances or as challenges that can be overcome. Interviewees describe

^{viii} Frank associates being tall with what he defines as the common understanding of success. Therefore, according to him, being short, and 'looking up' represents an advantage in so far as it allows him to 'play' with these stereotypes.

not only height as such, but height in relation to other specific things and situations as at times inhibiting and at other times enabling them, and as coshaping what they could be and do, and their attitudes towards the world. This is not to be understood in a deterministic sense, as, for instance, the same interactions assume a variety of meanings in participants' narration. Each interviewee describes how these situations and interactions play a role in coshaping her or his meaning of height and consequently of their 'I can'. According to our framework of analysis, we read such coshaping as influenced by each interviewed individual's perceptions of the world, others, themselves, their specific situations as embodied women and men, immersed in the sociocultural situation in which the interaction takes place. Once again, height assumes a meaning that transcends the relevance of height in centimetres, and that is open to the ways individuals envisage themselves and interact with others and things.

Height is gendered

The third and final theme centred on interviewees' narrations of gendered beliefs and norms, in relation to height. On a number of occasions, interviewees explicitly suggest a relation between masculinity and tallness and between femininity and being 'petite'. Jennifer claims that for her brother, who is 173 cm, it is a problem to always be the shortest among his friends because 'it's more masculine, I guess, for a guy to be taller than a girl'. In the same way, being tall is masculine for a girl because, she says, a really tall friend of her looks masculine. Masculinity is further described via terms such as 'control' and 'protection'. Frank recounts that he did not feel in control in intimate moments with his previous girlfriend, who was taller than him. At first, her stature was not a problem. Only after a while, he did realise that he did not like to have sex with her because 'it did not feel right':

I found it difficult to have a sense of control. And it is not that sex for me is about control, or power, or something. But, it is... yeah... you have to play with this...with this...[pause]... with this... power... Yeah, Shit. How should I explain this? You know what I mean? Sex is not about power, but, in a way, it is also about submission, sometimes. It can be. And it can be both ways. But it did not feel equal. We could not shift equally in both those ways.

Frank's narrative consolidates the dualism between two opposite gender identities: men are supposed to be tall and have a sense of control, while women are supposed to be short and (more) submissive. This theme recurred with all interviewees: while men say that they prefer their female partner to be the same height or shorter than them, interviewed women say that they do not find short men attractive. Hannie holds that she would not date a short guy. She defines tall men as 'more manly' because, she says, she never saw the short boy who was in college with her 'as a potential [boyfriend]'. Sophia states that she prefers a taller man because she feels 'safer' and 'more protected'. She also says that it is a 'natural feeling': men want to 'protect' their women and their families. Similarly, David says that with a taller girlfriend he sometimes 'doubt[s]' his masculinity because he likes the idea of being stronger than her and being able to protect her, but also because in intimate moments it is easier and more practical if there is not too much difference in height, or if he is taller.

Participants also describe how they negotiate these beliefs and norms. Milly, for example, holds that sometimes it is a disadvantage to be a short woman, while sometimes it is an advantage. She dislikes when others underestimate her, assuming that she is a kindergarten or primary school teacher, namely, what she defines as one of the 'standard women jobs'. At the same time,

being aware of the image that *others* have of her (as 'sweet' and 'cute'—this is also how short women are portrayed in all the interviews) is something she can turn in her favour: sometimes she can 'use' it to get what she wants. Linda, instead, states that, even if she does not like to be short, it is not as bad as other bodily marks. She tells that her colleagues at work call her 'tiny Linda', not to mistake her with another (taller) Linda. And this is not something that bothers her because:

I think it would be worst if they would say 'fat Linda'. I mean, I am also fat, but I rather have them tell me that I am small than that I am fat. So...

Even though she describes short stature as something negative, she portrays being fat as somehow worse—as if those aspects that she narrates as perceived limitations of short stature were not as problematic as the social norms about fat bodies. Through this narration, Linda creates a hierarchy of values, and in related ways Frank claims that he worries more about having poor eyesight than being short, and Hannie says that if she were ever bullied it would have been because she was a 'nerd', and not for her height. These narrations highlight an ongoing negotiation of norms and beliefs, which takes different shapes in different contexts.

However, this last theme also shows how gendered assumptions and norms about bodies are sometimes taken for granted and lived rather than reflected on, and sometimes negotiated, and how in both cases they can help shape interviewees' ways of thinking about height when explicitly asked about it. Again, we make use of a phenomenological notion in order to shed light on how some of these gendered norms can be deeply rooted in one's habitual way of being-in-the-world. Drawing on Merleau-Ponty's discussion of how objects and skills, through habituation and repeated motor activity, can come to be incorporated into one's lived body, more recent phenomenological literature has suggested that it makes sense to think of certain types of shared cultural patterns of understanding—including gendered behaviour and norms about bodies—as habitually *incorporated* in this fashion. Individuals may appropriate some such behaviours and norms through repeated actions, over time, and through continual practice, such patterns of behaviour can make their way into the pre-reflective bodily layer of our being and congeal as more or less fixed socially shared habits; they become incorporated into one's lived bodily existence.^{41 42} And one of the analytic points of this understanding of gendered patterns of behaviour is that it can help explain the elusiveness of gendered assumptions and norms that primarily are at work in the taken-for-granted domain of bodily existence.^{41 42}

As incorporated, such assumptions and norms 'belong to that *from* which we make sense of the world, act and interact, and thus rarely present themselves as that *to* which we direct our attention' (Malmqvist and Zeiler, p. 144),⁴² and only if something happens—that make us *excorporate* these previously lived assumptions and norms—we can question them. Further, such excorporation is by no means easy, and the assumptions and norms might, at a later stage, be reincorporated.⁴²

The phenomenon of more or less taken-for-granted (and because of this elusive) gendered norms can help explicate participant's narrations about partner preferences. Frank illustrates this well when he narrates how he just could not question

gendered norms when it came to his partner.^{ix} As seen above, Frank had a taller girlfriend and at first this was not a problem for him; he even described a certain sense of satisfaction in showing him and his girlfriend as a couple to *others*. After a while, however, he realised that the idea that he could not be 'in control' was so deeply rooted in him that he finally split up with her. Even if he described a satisfaction at the public display of them as a couple, and even if he explained that he tried to question norms about masculinity, control and height, he could only do it up to a certain point.

THE CONTRIBUTION OF SOCIOPHENOMENOLOGY OF THE BODY TO DISCUSSIONS ON HGH

Elsewhere, it has been argued that phenomenology can contribute to bioethics through its examination of how certain norms about bodies can become taken for granted and help motivate surgery intended to make bodies conform to specific norms, and the examination of what this means for individuals undergoing a particular treatment.^{59–61} Such research invites readers to critically think through assumptions and norms that they—we—at times might 'just' live. Phenomenology also offers an alternative *perspective* in the sense that it attends to existential and lived dimensions of bioethical issues.^{62 63} The analysis offered so far does both: it spells out lived experiences and (gendered) norms about height and it provides an alternative understanding of height that, as we will argue in this section, can enrich bioethical discussions.^x

To sum up, our analysis has shown how participants make sense of height in three main ways. First, height is narrated as an active engagement in space. Interviewees talk only occasionally of their height as a bodily characteristic that they observe as an object, external to them, from a distance. Instead, they focus on the ways they move in space, do things and relate to others. They narrate height as an activity. Height is described not in numbers but in action, not merely as a physical or aesthetic characteristic of their bodies but as an engagement with the world or as we have called it: 'heighting'. Second, height helps shape participants' habituated bodily agency, in diverse ways, and bodily agency is also shaped in relations with others and things: some places come to be perceived as inhospitable and some people as familiar, in the same way high shelves might be perceived as unreachable. Such a variety of meaning-makings is shaped and understood in relation to one's embodiment as a person that identifies with a specific gender, cultural community, certain abilities and so on. Third, perception and narrated lived experience of height is closely related to gender norms and beliefs. Interviewees narrate assumptions and norms about gendered bodies as more or less self-evident, and taken for granted, and draw on such taken-for-granted assumptions and norms when describing themselves as short women or short men.

This analysis helps us understand how height can be lived, and it attends to assumptions and norms about height—not merely

as potential problems—but as shaped in and shaping encounters with others, in different ways. This, we will now argue, is also a contribution to biomedical and bioethical discussions on hGH treatment: this sociophenomenological analysis of short stature as lived can be used to underline the need to move beyond a one-sided focus on potential problems that short stature might entail, without glossing over interviewees' narrations and accounts of situations that they do describe as painful.

The sociophenomenological analysis demonstrates the shortcomings of seeing short stature through the lenses of the problem-oriented approach and brings forth how the experience of height varies and unfolds in and through lived encounters. To recognise these aspects of height as a lived phenomenon adds nuances that are important also for ethical discussions, and this understanding of height is different from the one where objective height and quantitative measure in centimetres become central. As shown above, height in centimetres was mentioned only briefly by interviewees, who do not narrate it as having fundamental relevance for their daily lives. They rather focus primarily on their embodied ways of being shorter than average, which assume different meanings in interactions with others and objects, and the overall appreciation of one's body. We suggest that this understanding of height, at the level of lived experience—which still acknowledges the physical body of a certain height, but through the first-person experience—should be the starting point for discussions on hGH treatment in children with ISS.

Taking such a perspective seriously would require moving away from the idea of objective height as central to discussions of psychosocial disadvantages or problems, and of such disadvantages and problems as possible results of short stature, or preventable by increasing height—that is, moving away from ideas that were central to what we labelled a problem-oriented approach to hGH treatment. While we acknowledge that some individuals can experience short stature as troubling (and as troubling in some situations more so than others), we are concerned that explicitly *focusing* on possible disadvantages in discussions of ISS risks imposing a partial sensitivity to the issues at stake. Indeed, such framing might send the message that some psychosocial disadvantages are to be expected because of the child's bodily deviation from the average, thereby reinforcing negative assumptions about short stature.^{xi} Let us illustrate this point with an example.

The short-stature-specific quality of life measurement (QoLISSY) is a questionnaire developed to be used in different languages and countries. It has already been tested in several European countries (including the Netherlands)⁶⁴ and the USA.⁶⁵ The QoLISSY aims to assess possible effects of hGH treatment and psychological interventions in children diagnosed with short stature.²⁵ This instrument has been designed for a health-referral population (children and adolescents already referred to an endocrinology clinic) to be used in research and clinics,^{25xii} for both children who are undergoing hGH treatment and those

^{ix} Elusive norms are norms that are taken-for-granted in many everyday situations, and thus might be difficult to express. Such norms can nevertheless help shape behaviour. For discussions of elusive norms, phenomenology and bioethics, see, for example, Malmqvist (2014).⁶⁸

^x Our interviews might be analysed and discussed from different angles. For instance, Lakoff and Johnson (1999)⁶⁹ talk about high/low and up/down metaphors. However, they do so with a very different focus. While they aim at exploring the nature of embodied cognition, our approach instead relies on embodiment as understood by Merleau-Ponty.

^{xi} For a discussion of the role of measuring tools and charts in creating the way we currently assess pubertal development and sexual maturation, see Roberts (2016)⁷⁰.

^{xii} QoLISSY is used for both GHD and ISS, despite their difference in diagnostic and treatment rationale worldwide. While children with GHD have a dysfunction of the pituitary gland, children with ISS do not. Since GHD children might have non-height-related health problems (e.g., metabolic functioning and bones growth), hGH treatment is justified for GHD because it is not only limited to height increase.

who are not.^{xiii} The QoLISSY consists of Likert-scaled framed statements, to be asked to parents and to short children/adolescents (8–18 years old). Below we list three of these statements (the first two to be addressed to the children and last one to the parents):

- ▶ ‘Because of my height, I have more trouble reaching things than others my age.’
- ▶ ‘I have to look up at others my age when I talk to them.’
- ▶ ‘My child worries about what people might say about his/her height in the future.’

According to the QoLISSY, the higher the answers’ scores, the lower the child’s quality of life (they can choose their answer among the limited nuances offered by replying between 1 corresponding to ‘never’ and 5 ‘always’). However, this tool frames the assessment of quality of life of children with short stature in a way that cannot recognise or appreciate the different meanings that emerged from our interviews’ analysis. Let us explain how. In the first question, the use of the word ‘trouble’ refers to something negative, but it is not clear in what ways and to what extent children are affected by these ‘troubles’ in their daily lives. In the interviews, most of the participants refer to some kind of limitations in their relations to objects. These limitations are most of the time *not* described as problematic. Participants say that they have to make a number of considerations before doing certain things, and while these limitations sometimes are described as troubling, this is not always the case. Therefore, *assuming* that an affirmative answer to the first statement is inversely proportional to the quality of life of this child and adult-to-be is misleading. Second, ‘looking up’ is interpreted in the QoLISSY as negative. We have seen above, however, that while this sometimes is the case, there is more to it: at times, looking up was described by our interviewees as positive or as neutral. Third, the statement uses the word ‘worries’ while sometimes people might simply wonder about what other people would say of them. This does not mean that people have an overall negative appraisal of themselves (see above the case of David who, looking at his picture, wonders about other people’s opinions, yet often describes his bodily stature in positive terms).

The QoLISSY is an illustrative example of how common understanding of height as something negative (because of *presumed* potential social discrimination) risks limiting the interpretation of short people’s lived experience and overestimating the role of hGH treatment.^{xiv} It exemplifies the problem-oriented approach to justifying hGH treatment for children with ISS: the focus is on potential problems of short stature, not on different meanings and experiences of it, and quantitative measurement becomes central. The sociophenomenological analysis, by contrast, calls

for more open discussions of how short stature can be experienced. It can be understood as underlining the value and need to leave room for analyses of the lived experience of short stature. Given the recent debate in biomedical and bioethical literature on the need to restrict the use of hGH for ISS, an approach centred on lived experiences allows nuanced discussions that consider the child’s meaning-making within her or his sociocultural environment.

CONCLUSION

The prescription of hGH treatment for children with ISS is controversial because there is no proven relation between psychological and social problems and short stature. There is also a lack of evidence that hGH treatment might have positive outcomes for children’s well-being. Based on our interviews’ analysis, and the understanding of lived experiences of short stature that it portrays, we suggest a shift in perspective. Rather than following the problem-oriented approach that looks at short stature (understood in terms of objective height) as possible cause of psychosocial problems, we argue for the need to focus on the lived experiences of children who are shorter than average and be open to the richness of meanings that they can give to their height. Making a phenomenological analysis of lived experience allows for recognition of the role of embodiment for subjectivity; how the lived body is and sets the conditions of possibility of perception and action. It allows, as seen, to show how height helps shape participants’ bodily agency, in diverse ways, and bodily agency is also shaped in relations with others and things.

Based on our analysis, we suggest that the rationale for intervention should not be the prevention of possible risks but the actual lived experience of the child. Besides psychological and medical tests, the lived experience of children should be investigated before making assessments for hGH treatment. Taking again the example of QoLISSY, since it is a multiple-choice questionnaire, we believe that it has some structural limitations on what it can grasp about lived experiences.^{xv} While it might be useful to think of different formulations for the current questions, this would not address our main concern about the limitations of QoLISSY to capture the nuances of living with short stature. This tool should instead be complemented with narrative approaches attentive of children’s lived experience. The question should not be *whether* short stature in itself brings problems, but *how* the specific child might see and experience her or his height, given the sociocultural context in which he or she lives. This does not provide clear-cut answers, but it underlines the importance of looking at children’s well-being as something beyond their bodies in statistical comparisons with others. While individuals’ experiences are always affected by sociocultural meaning, the ways in which this happens might be multiform and we should pay attention at not limiting these meanings to common-sense assumptions.

We see three limitations of this study. First, because of the recruitment methods (especially the involvement of social network and snowball sampling), some of the participants know each other and have similar backgrounds. Most of them have higher education level. However, they are different ages and they live in different areas of the country. Second, since English

^{xiii}The lack of distinction between children who are undergoing hGH treatment and those who are not is problematic because technologies might shape their experiences differently.⁷¹

^{xiv}Other ethical considerations should be made about the QoLISSY questionnaire. Among these, since the questionnaire is to be provided to children who have been referred to clinics, factors other than short stature should be taken into consideration. Given that one’s meaning-making is shaped intersubjectively, and in continuous exchange with others and things, a comprehensive ethical evaluation should also consider, for instance, the way doctors and families explained to them their need for further medical examinations. Moreover, QoLISSY is used with both children who are taking the treatment and those who are not, but it is likely they might have different lived experiences and, consequently, meaning-makings of short stature (because of the administration of treatment itself and the way it is justified to them, and with them).

^{xv}See, for instance, what one of us has written on the limitations of a quality of life tool in oncology aftercare for the understanding of lived experiences, and how narratives can improve such assessment (see Slatman (2011)⁷²).

is not a native language for both the interviewer and the participants, we are aware that some meanings might have been lost. However, all the participants are fluent in English and looked at ease during the conversation. Additionally, one of the authors is a native Dutch speaker. Third, participants were asked in the interviews how they experienced short stature in everyday life and could choose to talk about both present and past experiences. The decision to let participants choose the experiences they wished to talk about was motivated by our focus on subjective meaning-making. For this reason, we did not make a sharp distinction between recollection of experiences that were recent and those that were more distant. Having said that, we acknowledge that temporality matters in the sense that recollections of events that are recent can be more detailed (and that recollections always are selective, and that all narrated experiences, of course, are recollections).

We believe that further research is needed in the biomedical and bioethical debate of using hGH treatment. For instance, it is an open question whether it should be made a distinction between ISS and other conditions currently treated with hGH or not, such as Turner syndrome or small for gestational age. Moreover, more critical research should be done on how and why (gendered) norms about height are so deeply rooted and how they can affect children. Finally, there is need for further research that problematises biomedical and bioethical debates on ISS and other medical interventions that aim to modify children's bodily marks that deviate from statistical norms, such as oestrogen treatments to reduce tall girls' height, orthodontic braces and intersex conditions.

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